

Daughterhood the Podcast

Episode #52

After Caregiving with Connie Baher

1:05:57

SPEAKERS

Connie Baher, Rosanne

Resources Mentioned in the Podcast:

www.conniebaher.com

Connie's Book [*Family Caregivers: An Emotional Survival Guide*](#).

Next Avenue Article ["When the Caregiving Ends: Recovering from Loss, Rebuilding Your Life"](#)

[Next Avenue](#)

Life Planning Network: <https://lifeplanningnetwork.org/>. Their mission statement: "The premier networking and professional development organization for life planners working with people over 50."

Clearing by Martha Postlewaite -

Do not try to save
the whole world
or do anything grandiose.
Instead, create
a clearing
in the dense forest
of your life
and wait there
patiently,
until the song
that is your life
falls into your own cupped hands
and you recognize and greet it.

Only then will you know
how to give yourself
to this world
so worth of rescue.

Arthur Kleinman The Soul of Care <https://www.amazon.com/Soul-Care-Education-Husband-Doctor/dp/0525559329>

00:01

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Rosanne 01:06

Hello, and welcome to Daughterhood the Podcast. I am your host Rosanne Corcoran, Daughterhood circle leader and primary caregiver. Daughterhood is the creation of Anne Tumlinson who has worked on the front lines in the healthcare field for many years and has seen the multitude of challenges caregivers face. Our mission is to support and build confidence in women who are managing their parents care. Daughterhood is what happens when we put our lives on hold to take care of our parents. We recognize this care is too much for one person to handle alone. We want to help you see your efforts are not only good enough, they are actually heroic. Our podcast goal is to bring you some insight into navigating the healthcare system provide resources for you as a caregiver as well as for you as a person and help you know that you don't have to endure this on your own. Join me in daughter hood. Connie Baher is a writer and speaker on caregiving and reimagining retirement. Her latest book is Family Caregivers an Emotional Survival Guide. Published in USA Today, The New York Times Magazine, Forbes and the Boston Globe. She is also the author of the case of the kick ass retirement. She is a Harvard MBA and entrepreneur and a former tech executive. Connie is a frequent contributor to Next Avenue. And I had the pleasure of being a part of her article When the Caregiving Ends, Recovering from Loss Rebuilding your Life. Today, Connie and I discuss life after caregiving, the variety of emotions to wade through dealing with others while you're grieving. That inevitable question of now what do I do? And so much more. I hope you enjoy our conversation. Such a large topic, Connie. It's the end of your caregiving years, the end of what you've been spending your time and worry on day after day, for however long you were caring, and then poof, it's all gone. Even if you were expecting it, it's still shocking. The caregiving peace, the purpose, peace, the end of an era. My first question to you Connie is what do we do with that overwhelming thought? Now what? Where do I go from here?

Connie Baher 03:11

Yeah, well, let me sort of backtrack a little bit as you tee this up. So well. I think when the caregiving ends, it does leave people feeling up ended. And it's perfectly normal to feel totally overwhelmed, off kilter and confused when the caregiving ends. But to put it in context, if we take a step back, and caregiving as I've come to think of it, and I know as you probably in many of your listeners have experienced, it's like this giant funnel, you start out at the narrow end of the funnel, and you're helping mom or dad with the groceries, or you're holding I see people holding their spouses hand as they walk unsteadily and a bit bewildered, that taking person to the doctor. But as time goes on, the caregiving tasks grow, and pretty soon it takes over your life, and you're on call 24/7. Right? And so even if you're not a hands on caregiver, I think it counts my definition is very broad. If you are a care coordinator, if this person is on your mind, day and night, you are a caregiver, so it becomes this all encompassing job. And I think the other thing about it, and maybe this isn't recognized enough, is it creates an incredible intimacy with your person. I mean, you may be doing their laundry, bringing them food, helping feed and groom them. You're attending to their every need. I mean, in some cases, I know of my cousin that took his wife to the bathroom every day. I mean, talk about you know, an intimate relationship that you never had expected. And so no matter how much and I think you've talked about this, no matter how much you may have anticipated the end, the caregiving ends. And suddenly after months and years, let me tell you how it happened for me. I was caring for my mom for 13 years. And suddenly, it was over. It was just after midnight, on a Monday in December, the phone rang. And a voice from skilled nursing said, I hope I can say this without tearing up. I'm sorry to tell you that your mother passed away at 1210 this morning. Oh my god, it's over. I that's what I said to myself, not out loud, but to myself. And I felt a clutching in the pit of my stomach. I said, Oh, my God. It's finally over. And I think you know, it's sort of like the person who's been walking into a gale force wind, and suddenly the wind stops. It's a shock. I mean, even if, you know, in my in my case, it was so clear that the end was coming. My mom wanted to go, it would have been a release whenever it came. But it left me feeling disoriented, unmoored off balance, Nam, in a fog, all those things. So this question of where do I go from here? What do you do? You got to tell yourself, you're not going crazy. And this is normal. And you start ever so slowly and patiently to reconstruct your life.

Rosanne 06:47

Totally agree. And I should say, Your mother was how old when she died?

Connie Baher 06:51

105. Not not unexpected. And and it's, I know, there are many, we could talk endlessly about the unique situations we all face. This was not what they used to call a premature death. This was certainly something but it still comes as a shock.

Rosanne 07:12

That's, that's why I bring it up. Your mother was 105. And you were still shocked when she died. Yeah, even though you knew you were that's where you were going. And you know, listen, we all know, nobody gets out alive. Right. And, but she was 105. And you'd been caring for her all this time. And it still took you by surprise. Because, again, who Yeah. And, and it's and you're left with, because it's not just your person. It's not just your mother, it's not just your father, whoever you're caring for. You've lost that schedule, you've lost that everything that you do during the day was was around them. Everything from the minute you wake up to the minute you go to sleep, if you do go to sleep, even when you do

sleep, you're still in, you're still on duty, as I like to call it. And so it's it's more than that. It's it's your entire schedule is your entire day. It's your entire being. And by the way, you just lost your person. And, you know, how do you keep How do you cope with that? How do you how do you look at that, and your idea about acknowledging Yeah, I'm not crazy. This just happened. But how do you cope every day with that when every day is a reminder?

Connie Baher 08:22

Yeah, yeah, yeah. Well, I think an a key part of it is, so as you've as you've set it up, so my mom was 105. And I knew we all knew and it was my goodness, in the grand scheme of things. She was going to die and you know, right, okay. But the diff the thing about it, I suppose maybe we look at it this way. If it's your great uncle who dies at 105, you send a condolence note, you go to the funeral, and life goes on. But when you have been, as we said earlier, this intimately involved with perhaps more so than you ever were before. And so your entire life stops. And I think what can happen is that people feel they've lost their purpose, their sense of purpose. I talked about this because I've written a book and written a number of articles about caregiving and interviewed Oh, probably 150 people, some caregivers and some who are what I think of as the pros, the counselors, the hospice workers, the social workers, so I, I talked about this with a bereavement manager at a hospice her her name is Adriana Hernandez and I said, What do you do when suddenly the caregiving ends? And you've been intensely entwined with this person and she said, you can lose yourself to the point of not knowing who you are any more. You So here's my prescription. Not that I'm an expert, but I've certainly walked the walk. Rosanne, you've walked the walk, the first part of it is ease up even more radically. Don't ask what your new purpose is, at least not yet. So I think step one is actually being handed to you, you may feel numb, you may feel that you're dissolving into tears, you may feel strangely off kilter. But you do have some work to do immediately afterwards. And this is going to help you move forward, you have to clean out there, you have to distribute their possessions, maybe you are the executor of your will. And maybe you move through these tasks, sort of like a zombie, but they can be the start of your healing. So that's step step. One is they said, I think step one is, in a sense, is handed to you. These tests are different from what you did as a caregiver. And I wanted to pick up on something that something you said really sparked this thought, you know, before they die, you probably say to yourself, how long is this going to go on. And as it continues day, after de, you, you, you say, well, maybe maybe in a sense, that psychologically, you feel it's gonna go on forever. So all of a sudden, it does end, which is such a surprise. But now, let me get back to this business of this step one is these tasks that get handed to you, they are different, they have a beginning and they have an end, they may not be fun, but they are something that starts and finishes, you need to pay the hospital bill, you do it. And it's and it's done. You need to move their belongings out of the hospital room, you do it and painful as it is, it's done. And so in some ways, these cut and dried tasks, I think, while they're while you're doing them, you may not realize it, but you're beginning to move forward, the slow process of healing, I think, is starting to take root in the background. And as for the rest, I think the rest is going to unfold in its own time. For some people, and you're a wonderful example of this. They find themselves wanting to share what they've learned. So they stay on in bereavement support groups. They work as you do offering podcasts or writing books or articles is I have I'm in a few weeks, I'm going to be leading a support group for for caregivers. For me, I can feel the energy of caregiving propelling me forward to work with other caregivers. I mean, it may change at some point. Sure. But I think the key is, is not to push it. And the

secret to finding your new purpose, I think is simply patients. Yeah. And if I could, Can I Can I read a short poem? Because I think it encapsulates it so well.

Rosanne 13:02

Absolutely.

Connie Baher 13:03

It's one of my favorite poems, and I've done a lot of work and research in the in the whole field of life transitions. And this is a major life transition. Right, and, and this is a poem that encapsulates what I think is a profound truth about purpose. Maybe Maybe you know what it's called the Clearing, by Martha Postlewaite, very short, you know, it right. It says, Do not try to save the whole world, or do anything grandiose. Instead, create a clearing in the dense forest of your life and wait there patiently, until the song that is yours alone to sing, falls into your open cupped hands, and you recognize and greet it, only then will you know how to give yourself to the world so worthy of rescue. That's it, that's it, give yourself a chance to find that clearing and be patient.

Rosanne 14:06

I mean, that's beautiful. And it's it's very true. It's it's so hard when, you know, I cared for my mom in my home. And to to have it was it was so difficult for me. Because she was in my home. I mean, that that was it. Like, I would get up and walk down the hall. And it was like, Well, I'm not walking into her room. I'm not doing that. I would go to the store, which was a new thing because I didn't need to organize her or figure out who was going to sit with her while I went out. And I remember I remember when the priest called for the funeral and he said, we have to come down. We'll have to come down to me. And I was like, okay, and the first thing I thought of was, we're gonna have to get somebody to sit with mom. And it was like, oh, no, you don't Those types of things are very strange. And it takes a very long time to get used to. And, you know, coming home and pulling in the driveway and being like, Oh, I'll tell No, she's not there. Those things play with your mind. And of course, that's part of grief, because we can't just, we don't just go from point A to point B, and everything's great. You're grieving. And the grief that's involved in this, along with, what do I do now. That's what creates this, this being off balance. It's, it's this, I don't know what to do with myself, because I haven't had to do anything with myself. For so long. mot, I wasn't the top of my list. And now your list is gone. It's been erased. And it's like, okay, well, now what? I don't know, I just want to sit here for a minute. Can I just sit here for a minute? And the answer is yes, you can sit there for a minute. You, you're, you're not going to you're not going to finish caregiving, and immediately go, Well, I always wanted to do blah, blah, blah, I think I'll do this. You can't, it doesn't work that way. And I think your point of giving yourself that time, it's okay to give yourself that time, you're not going to have all the answers, you can't have all the answers. You're, you're not even firing on all pistons yet. And then when you throw in, you throw in that lovely guilt that comes with that, you know, people may feel like you said, you felt relieved, okay, some people could feel relieved, and then feel guilty about feeling relieved, or feel guilty about not being there or not doing enough. And I've heard from caregivers who have grief over being so focused on everything they had to manage. It's almost like I paid so much attention to what I was doing. I forgot about my parent. I forgot about that relationship. And, you know, that's, that all goes with it. And I don't know, do you have any sense of of strategies that would go with dealing with that guilt? During that time? Like, we're going

to put the we're going to put the what should I do now? Yeah. And deal with with that guilt that comes with all of this?

Connie Baher 17:09

There's there's tremendous amount of guilt, I think, and let me pick up on something you said that is so true. As caregivers, we have all these responsibilities. So maybe even routines, you walk in, and you say, Have you taken your meds today, or you walk in, and you give the meds today? And now you look around? Is there enough insurer, oh, she's run out of Kleenex? Oh, I have the doctors calling. And you very often as caregivers, we don't have the bandwidth to sit there. And, you know, just talk about some wonderful times we used to have together, it's very, very hard. And just for any of your listeners who are current caregivers, let me offer a suggestion about that. Bring a friend, bring a friend who would like to meet your person. Obviously, you don't drag somebody who's scared to death to see a hospital room where to see someone who's who is failing. But if they say, you know, I'd like to meet your mother or your spouse or you know, would you like me to visit very often, if you bring them number one, it's less frightening for the person, the friend. But the other thing is, that friend does not have the same responsibilities you do. And that friend can sit down and say, Well, Bob, tell me about your life or, you know, tell me about when you were in the war, or tell me about this, or let's and they can provide some of that other wonderful stuff, and joy and all that you would like to see in your person's life. But that, let's be kind to ourselves. We've got so much else going, you know, we just may not be able to do it. So, so bring a friend bring a friend. But if I may, let me pick up on the yellow thing as I think there are at least three kinds of guilt. The one is, you touched on this if you feel relief when your person dies. Here's a here's a person her her name is in some of the names I'm going to mention our disguise, but this her real name. Her name is Judy Smith. She's a former English teacher and a Peace Corps volunteer and she brought kind of a little bit like you she brought her ailing mother to her home in Washington, DC. And she told me her bedroom was across the hall. After she died. I felt guilty that I had the freedom. I felt guilty that I could sleep through the night. And then I talked with a hospice social worker in Southern California. Her name is Selena. And she said it's the number one thing people tell me afterwards. They feel so guilty. They say am I a horrible person to feel a little relieved? and Selena says there's no need to feel guilty, it is perfectly normal. She said being a family caregiver is the hardest job in the whole world. And it is natural to feel some sense of relief. So give yourself permission. I think there's certain kinds of guilt. And it's the guilt of this is a huge one not being there when they die. Yep. You stepped out for coffee, you went to the bathroom. And when you came back into the room your person had passed. And after all, I mean, wasn't that the goal? Maybe it's unspoken, but you were going to take care of them all the way to the end. And then you're not there when it happens, as if this giant project was left incomplete, or worse, that you wanted to hold their hand and be there when it happened, and you just weren't. So here's the reality of Barbara, as a hospice worker, when my mother in law was dying, and she told me, we said, my husband and I said, Well, is it time? Should we go and have a vigil, sit by the bedside? And she said, No, she said, most people aren't there when their loved one dies. And let me make it clear. She wasn't discouraging. She said, Look, if you want to do that, absolutely. But as time days go on and on and it's unpredictable. And how much sleep do you want to lose? And are you really helping? And she said, most people aren't there when their loved one dies? And let me i This is my favorite Carmel Murphy-Kotyán is a woman who runs a homecare business in Massachusetts, and she is an end of life and grief coach, she goes even further. Here's what she told me. She said, it's as if they wait until you walk out the door. Yeah, I hear that a lot. She says there is nothing to feel guilty

about. People pass the way they do. Sometimes when they're by themselves, that's when they pass. There should be no guilt. It is a solo journey. Wow. And finally, guilt. Number three, guilt number three, the guilt of not having done enough. Yeah. And I think we can parse this a bit. And I think one part is the notion that you could have visited them more been more understanding, as we said a minute ago, I don't know played Scrabble with them Dun, dun, all sorts of things that you just didn't have time or you regret when you got angry, you should have been more patient. And of course, we all could have done more. But I think there's a sub current, maybe a deeper anguish, a sense that if only you would found another doctor brought your person to the hospital sooner, done more in some way that you could have kept them from suffering and from dying, maybe. But more than likely you did what you could with the knowledge you had at the time? Could they have lived longer? Perhaps a little bit? Could they live forever? Of course not. You are just a humble caregiver doing the best you can. There's always something we could have done, but ultimately, we cannot save them from death. I know it's getting a little bit deep, but no, no, you're right. How to deal with the guilt. I would say this try the best friend cure. If this was your best friend, what would you tell them? You would say? Oh my gosh, after all you've done for your person day in and day out. It's only natural that you might feel some relief when these heart when this heart wrenching journey is over. You would say? Stop beating yourself up. You would say it's only in the movies that everybody gathers at the deathbed. Yes. Yeah, right.

Rosanne 24:04

Uh huh. But yeah, right. Somebody has something profound to say before they die yes.

Connie Baher 24:07

Yeah, that's right. That's that's that's right. That's right, the old lady and the little white lacecap that everybody's right. Yeah. I mean, I know some people are at their person's bedside and they arrange for a harpist to be playing as their loved one quietly passes away. I mean, it's beautiful. That's wonderful. If you can do that, and and the fates align such that that happens. But we don't get to arrange everything in life. In fact, maybe not much in life. So you just stepped out of the room, you went down to the cafeteria, or that was the day that you didn't go to the hospital. It's okay. You gave so much to your person. You thought about them day and night, and you will continue to think about them and to carry them in your heart. So there's one more prescription Um, I think you need to talk to that inner voice that is beating you up and tell it to turn down the volume. And find instead of easy for me to say by the way, I love this prescription, I'm working on it day and night, believe me. Yeah, fight fight instead, the inner voice that is kind and gentle, and soothing. Let's listen to that one, listen to the voice that is calming you telling you that you are okay. You're only human. If there was something left undone, even left unsaid, that's the way it is, we aren't perfect. Listen to the voice that tells you you did the best, you could take a long deep breath, or two or three and bathe yourself in kindness.

Rosanne 25:50

Yeah, and it's, it's very hard. When there are those, there are those moments because sometimes you're in the hospital, sometimes you're in the emergency room, sometimes you're just home, when they pass. And those last moments as beautiful as they are, can also be traumatic. And it takes a while to get past that it's like last in has to be last in. First out. And to replace that. Because then that also leads to that magical thinking of well, if I could have done this, and if I should have done that, you know, the could have would have shudders. And it's almost, you have to replace those those memories, those

those scenes that play in your head with a positive thing. And I don't remember where I've read that you have such a great way of, you know, giving credit there. That's the writer and you Connie. I can't remember where I read it. Because I was trying to find as much information as I could in how do we get past this because as a caregiver, that is what you're left with, you're left with those memories, you're left with those visuals in your mind that you have to replace and it is a replacing with something more positive? How? How do we incorporate that? Because we're still, you know, we're talking about after caregiving, and it's such a long ramp, right? Because there are so many things before you even feel like a person again. Because if you were in a depending on the type of caregiving you were doing, and the exhaustion and all of that, that comes with caregiving, it's a long ramp before you get to the point of actually exhaling and being like, okay, and all of this, the guilt, the PTSD, the trauma, all of that is still part of that beginning part. And it's important to try to replace those because that will keep you stuck, almost. And I hate to say stuck, but it will it will keep you in that dark hole. And you have to try to find a way out of that dark hole. And I'm not saying to poopoo it. And I'm not saying to pretend like it didn't happen because it did happen and you witnessed it. But to try to give yourself that permission to look forward. Does that make sense?

Connie Baher 28:21

Totally. And I'm glad I'm glad you brought it up. Because I think what you're talking about those that last moment that that horrible moment. Let's let's back up, maybe you were there. Maybe you saw the person after they died. But whatever it is, there's generally going to be some terrible image in your head, even if it is even if you weren't there at the very moment that they died. But as they were sliding, I mean, I will tell you for me. I was my mom had had sort of what we think was the her final stroke. And so the without going into all of the gory details, but she's on the final medications. And I'm holding her hand her hand is bony, it is blue. Does she even know I'm holding her hand? I don't know. I'm talking with her to try to say soothing things. Tears are coming down my face. That image is you can tell it's still very vivid in my mind, but not as much as it was at the very beginning. And so and I do think I think it's a form of trauma. I really I really do. And I'm glad you brought it up. And I think that most of us unless we're in a healthcare profession, have never been this close to anybody, as they decline have never been there when they died. And I think it's searing shattering, and it does it lingers in our memories, especially in the early days, those memories can haunt you because they're just much bigger than any other. Other thought. It just crowds out any other thought you have about your person. And this is normal. I was I was doing a little bit of research on this stuff, too. It really relates to what researchers call our negativity bias. negative experiences are simply far more potent than positive ones. Yeah, they cut deeper, they last longer, they show up unbidden in our minds. And so the goal is, how do you drain the energy out of these negative memories, the pictures in your mind, you want them to fade? And you want to work as you said, you want to replace them or overlay them with good memories and positive experiences. So I do think, depending on how severe the situation is a good support group, even a good therapist, yes, can be of great help. But I think there were also some home remedies. So let me offer again, please do I think instead of trying to avoid the memory, take a full frontal look at it. When the here's one suggestion that others have offered, when the painful memories show up, try journaling. But the idea is what does that mean? The idea sit down with a piece of paper or in front of your computer and write down as a jack actively as you can. The facts of your experience. Social Worker, Amy Morin she says this, it may help you to reorganize how your brain has stored the memory. The idea is don't put the emotions into it just put her hand was blue, it was bony such as

succession such, this may help drain some of the emotion out of the memory. And help me help weaken it. The next time it comes around. So so try one thought is take a good hard look at it, write it down as as something objective, that's one notion. Another one is is what I think of as interruption and redirection. When you find yourself, I'm going to pick up on your word stuck, right? In the bad memories, try to interrupt the vicious cycle, you may have to force yourself, but shift to something else. So when the memories are coming up, do something that you enjoy, or that you used to enjoy. Because you know your heart is not quite in the whole thing you have to push yourself. So take a walk, listen to at least what used to be your favorite song, read a few pages in a mystery book, watch a comedian, or a good movie on Netflix even you know, a few minutes, just break the cycle, just just break it. I will tell you this, this comes out of diet techniques, what they used to say, I went through that I went through a long program losing learning how to lose weight. And what they said is when you have the urge to eat, you would have this rubber band around your wrist and you would snap you know this one, you just snap the rubber band Whoa, yeah, yeah, same same notion when when the bad memories. You know, as I said earlier, I don't want you to think that you have to avoid them. Because that's not smart. But when you and you'll know when it's right. But when you say you know it's coming around again, and I'm not making any progress. That's the time maybe to interrupt and redirect. And then the final home remedy is to dig for the good memories. It turns out that our long term memory is much better at storing negative experiences than positive ones. So if you're looking for the antidote to the painful memories, you've got to find the good moments that you had and the things you share the things you've learned from your person. And this is what social workers Selena told me, she puts it this way. She said sometimes you have to take an active role. None of us is just one moment. I really liked that. She says remember the whole whole life, the happiest moments. The ending, she says is such a small piece in this amazing life that they've lived. So here, here's how you can do that. After somebody dies, you know that people often find themselves searching for old photos, looking through old albums to put together a memorial service. However you do it, find those old images when your person was young and vibrant and hopeful and smiling. I found a picture of my mom she used to she just like to play golf. And she was there in her little little black and brown and brown shoes. And I guess they must have had spikes on the bottom. And this short skirt and his cute little blouse. And her hair was all brown and lovely. And she had this big smile. She's probably about 18 years old, life was all in front of her. I'm working on trying to think of that person. Right, as as part of this sort of Kaleidoscope this collage, if you will, of, of who she was. So I let me put it this way. Maybe you ever in your mind? Did you ever stand by a lake with your person, as the sun was setting and you'd say I want to keep this moment forever. Find those moments and build an inventory of them those beautiful, wonderful moments, and focus your attention, replay them dwell on the good feelings that these memories evoke. Because that's what you want to stick in your brain. You want the good memories to be in Technicolor, and you want the bad memories to fade into grey.

Rosanne 36:13

I love that. Yeah. It's so true. And it's so you know, all of this is what makes the after so heavy. And then you have the people that don't understand what you just came through what you just witnessed what you were just a part of. And unfortunately, in our, in our world, in our society, people don't like to talk about grief, they don't like to talk about anything uncomfortable. They don't like to they just want you to be happy. Just be happy. Aren't you happy? Isn't it better? Don't you? It's in the great now. Now you you get your life back. And it's like, no, I don't get my life back, I left my life back there. And I lost

little pieces of myself along the way. And now those pieces don't fit anymore. This is a whole new landscape. This is a whole new world for me. So it's it's not that, but how do you deal with those people that want you to just, you know, put on a happy face or, you know, you just have to go out? You just have to pick yourself up and do it like you just have to how do you what what is your what is your advice for that?

Connie Baher 37:22

I'd love to think about that. And also I think you've hit on something that is pervasive right now in our society. Happiness. There are a million podcasts about how to be happy. There are college courses unhappiness, we're obsessed with this notion. I mean, nothing wrong. I'd love I'd love everybody to be happy. But but there is somehow this if you're not there. There's something wrong with with you. Oh, yes. So the you're right, people, they want us to be happy. They want us to take the happiness courses, they want us to do all that stuff, and they're uncomfortable around our grief, I the I don't like it either. I don't want to make people cry. I don't want to bring up stuff. That that will I don't want people crying in front of me. Maybe this is also true, I think you'll find it in the caregiving situation with the siblings who can't come and help. A lot of people cannot deal with death. They don't want to deal with death. Denial is sort of their go to emotion. So your friends, they want you to cheer up and get over it because it's easier for them. So I I try to tell myself that they mean, well, actually, I try. You know, I think it's only a trap. If you say, here are my expectations for how people are going to react because they're going to do what they're going to do. And I think sometimes they just don't have the skills. If they've never, I've been guilty of this myself if they have never experienced a loss like yours. They just don't know what to do. And I think back to my younger self when I didn't know, I hadn't been there. I hadn't walked this this walk. I think the people want you to go back to being a person they knew, because that's something they can deal with. Or oh my gosh, they fall back into the cliches. It was all for the best. They are happier now in heaven. Yeah. It may not be what you want to hear. I mean, let me just go on that path for a moment. The condolence letters you get, I just I'm I think to myself, they mean well. Sometimes it's a hallmark, little bit of garbled poetry. They do the best they can. Occasionally maybe what you read is helpful most of the time, I think it's just tangential to where you you're at, but it's the thought that counts. They're trying to be of comfort, so fine. Let it let it go. So I think the way to deal with it is just to say thank you and realize that they're clueless. Right, you know, and they're just stumbling their way through this the same way, the same way you are right now, another thing. So that's one thing is just sort of have to let it go. But the other thing is, you can help them help you. You know, thanks so much for your consideration. I really need some time alone right now. Actually, I there's there's somebody I know. She just lost her husband is a good friend of ours. And we said, Gosh, we'd really love to have dinner with you. And she looked at us and she said, You know, I love that you're asking me, but I'm not ready yet. Can I let you know when I am? Yeah. This is helpful. This is wise. This is very mature. Or you might say, you know, yes, I would love to see you. And maybe we can share some memories of Joe. In other words, let them know what you need. And what I'm learning because again, I'm going to, I love to tell stories about my mom. They don't make me cry. They make me they make me feel good. They bring her back to me. So because I don't know, maybe you've you've seen this or again when I was before I'd been through this experience. I think Oh, I better not mentioned, Judy, because Judy's dead and that, you know, that's Bob's gonna cry. No, thank you. No. So,

Rosanne 41:35

Right, like they forgot. Oh, my God. Oh, you mean they're dead? Oh, I was wondering why she didn't call me back. No I know they're dead.

Connie Baher 41:45

But I do think you've talked about this is that you have to grieve on your own own terms. And every grief experience is unique. And oh, we got we I'd love to touch on this. Everybody has heard about the five stages of grief. In fact, somebody's even written. Thank you. Yeah,

Rosanne 42:04

Yeah makes me crazy, makes me crazy.

Connie Baher 42:07

Yeah, somebody's written a book about the six stages of grief. Well, and I can tell from your reaction to the more recent research says the grieving is not necessarily that linear. It's more like a zigzag, moving forward, revisiting the loss. And there is no playbook that tells you now's the time to move from denial to bargaining. Right. Okay. Let me tell you this story. This is Judy Smith whom I mentioned before, she lives in Washington, DC, and when her father died, there was just too much else going on in her life for her to grieve. It was only later and by herself, that she was able to grieve. So this what she told me, she said, four or five months after my father died, I went by myself up to West Virginia, and I stated and in, I sat there on the bed, and I wrote in my journal for four or five hours, and cried and wrote and cried and wrote, It was a very special time. So I think as long as you are open to how you're feeling and what you need, whatever you're doing is right. It's right for you.

Rosanne 43:22

I fully agree with I fully agree with that I I wrote my mother letters every day, after she passed, I would just I'd sit at her desk. And I'd write in the book. Hi, Mom, this is what happened today. still miss you, whatever. And I did that for probably a month straight. I would do it every single day I'd go in, I'd sit at her desk, and I'd write her letter. And it's lovely. You know, you have to do because you know, you have to do what works for you. Like you said it nobody can say to you go out for a run? No. I don't think so. But thanks for the offer. You have to find what, what is kind and compassionate to for you for yourself. Because that's you have to get back to that point of being back in your own body. And being aware of what you need and what can help you. And that's hard. Especially for caregivers. It's hard because we become disconnected. Because we fall down that list of where are you on the list. And I know that's all part of self care. And that's all part of everything and I get that, but the reality is we become disconnected. And to then come back to this and be in this position. You You have to find these things and I think you know, I like to think that we have to be open to things we have to be open to the thought of, well, gee, I I liked to do this before maybe I can try that or I've never tried you know crochet but I'll give it a shot, whatever I mean, insert, insert your activity here. But we have to allow ourselves to be open. And to try to follow our instincts, because I do believe that our, our minds, our hearts, our souls, talk to us. And I think we have to follow those instincts that come up like, oh, maybe I'll try this. Maybe I'll try tap dancing. I don't know. Do you know?

Connie Baher 45:23

Yeah, I think that's true. And I, as you're saying this, I'm thinking to that, again, as we, as we're framing this as the transition or the abrupt movement from the caregiving where your purpose was so clear, yeah. Your schedule, as you've said, Is your routine was so clear, of course, you put everything for yourself on the back burner, because you had this enormous, momentous and incredibly meaningful job that you that you were doing. And so in a sense, very externally driven. And now what you're talking about now is, Oh, that's right. There's no, there's, I love what you said instincts. Because I, that's what I meant earlier about things like patience, about letting life unfold. Let me introduce a word we haven't talked about, which is control.

Rosanne 46:25

Oh, okay.

Connie Baher 46:27

Because we love to, we love to be in control. We want to manage everything. And so this thing you're talking about, about instincts, and letting trying, this is just about the opposite of control. And so maybe as we're exploring this together here, you're making me think that this is also a shift from a very controlled, scheduled, very clear purpose. I mean, in a sense, I have to say, one thing I loved about caregiving was I didn't have to question my purpose. Right? It was, not only was it crystal clear, it was in my DNA, it was just coming from the very heart of, you know, the core of my soul to be to be doing this. So So now we're in a hole or transitioning into where we have to the clearing in the forest, we have got to quiet down, let it flow. I mean, there are all sorts of wonderful analogies here. But we have to, and I think, I think the idea of trying things testing out and the other thing, let's let's add most people to we could use the word the big D word depression. Oh, yeah. We don't want to think that we're depressed. Nobody wants to hear Hi, today, they want to hear the happy talk, well, actually on kind of depressed because my person has died, and I don't know where I'm at. So even if it's, let's say, short of a clinical depression, you better go see somebody for help. But even if it's just sort of a low grade sense of, there is no joy, I will probably never be happy again. The world is gray. You know, I've lost everything. And so what we, what we have to do, I think is push ourselves a little bit you've, you've talked about this, you may not feel like going for a run, taking a walk, maybe a walk in nature is not going to be the most incredible thing or you can't even enjoy a beautiful sunset. But push yourself a little bit because and we all know this and we've told this to our friends, that time will come and you will laugh again. So I think that business of just following your instincts. I'd like to think of taking things for a test drive. Try a yoga class or something you know, it's interesting think back and this goes back to the work I've done helping people when they retire because it's very similar situation, the structure of their work life is gone and they say oh my god, now what now? What am I good for? Right? Think back to the things you liked when you were in high school. What did you like to do? You'd like to read mystery stories or or it may be later in life. You did some knitting but you haven't done any knitting or crocheting or quilting and or you take out your paints and put up the easel. Small steps to you don't have Have to let's stick with the painting idea because you don't have to paint a masterpiece, right? You don't actually have to paint anything anything.

Rosanne 50:09

Yeah

Connie Baher 50:10

Find the paints, get some paper and set up the easel. That's it. Just do that. Just do that. And then maybe one day you'll soon maybe I can put a little bit of color on the canvas. And when and as you're ready, take take, take baby steps. That's the way you rebuild a life, right?

Rosanne 50:31

Yes, it is. And you can do this, whether your person died last week, or last month, or three years ago. It doesn't matter if you have this feeling of there's something more there's something it's almost like you have to focus on what's support you and not what drags you down. And it's that, you know, we get caught in, in the stories that we tell ourselves about what we can't do. Why couldn't do that? Well, why not? Yeah. Why'd who told you, you couldn't do that? Who told you you couldn't try this, you're allowed and a lot of it comes down to that permission, you're allowed, you're allowed to see what's different for you. And that might be a little bit of an exciting part that you can see, when you allow this to kind of sit and ruminate like, Okay, well, what? It's not in the beginning, it's a little scary, but as you as you move forward, but I think it's just, you know, you have to you have to be okay with giving yourself time and being open. And, and then in going forward carrying, how do we care for the memories of our people? How do we, how do we keep them present? What do we do?

Connie Baher 51:46

I love that. So they I got to start with one of my favorite books, the author's guy named, he's a physician, and his name is Arthur Kleinman, He nursed his wife through the ravages of dementia. And he wrote a book called The Soul of Care. and it's beautiful. It's a beautiful book. And here's the point that he makes that relates to what you just just raised. He said, care does not end with death, but involves actively caring for memories. Wow. So how do you do that? I think you can commemorate their passing. You can I've been doing this recently. And I was surprised how satisfying it was. You can make donations small, small in their name. I mean, my mom used to, she had an incredible empathy for anyone on this planet who was suffering. So if there would be a flood, she would want to give to the Red Cross for flood victims, that sort of thing. And so I mean, it talks about 10 \$15, or whatever you can afford, but that it, I have found that I would give to the International Refugee Committee. Because I knew that that was something not only that I cared about but but I was sort of carrying through her legacy. So you can you can do, you can do those sorts of things. But also caring for memories can be very tangible. So here's here's my friend Judy Smith. She makes fudge from her mother's recipe every year at Christmas time. That's what she knows.

Rosanne 53:37

Judy's my kind of girl. I love that.

Connie Baher 53:40

Right? Right? You know, the recipes that mothers and wives leave as their legacies are incredible. There's a widow who keeps her husband's bathroom, bathrobe on a hook in the bathroom. Okay. And that's how she keeps you know, I mean, I have to say, I wore my mom's bathrobe for about two months after she died. It felt warm and comforting. And then at a certain point, I realized it looks terrible on me. And I said, and it's it's it's done. It's had its again, you listen to those instincts. It felt I said, How long will I get? Well, until it doesn't feel right anymore. Till it doesn't feel necessary until it doesn't. That's right.

Yeah. You know, there's the son who keeps his mother like my mother was an artist. He keeps his mother's pastel of an Italian landscape by his desk, where as he told me, he said, it radiates her energy to me every day. And so I want to tell you about this I as I said, I'm I'm lucky that my mother was also an artist and one of the things that she did was she painted cards, beautiful flowers or energetic, colorful abstracts. And she had so few ways of expressing her thanks to me, she was very grateful for what I was doing. And she said, What can I do? How can I excuse to say, How can I ever thank you enough? Which and I was lucky I it's true that not all caregivers get the things more if the person has passed into dementia, and cannot speak. So I was lucky. I was lucky. I got that beautiful feedback. But she said, How can I ever thank you enough so she would give me these beautiful cards. So I'm surrounded by the cards at my desk on display and bookcases. But just the other day, I realized there's another way I can keep her memory alive. I'm using the cards now to write to our grandchildren. So the cards are tying three generations together.

Rosanne 56:01

That's beautiful.

Connie Baher 56:02

Isn't that nice. Yeah, yeah.

Rosanne 56:04

That's beautiful.

Connie Baher 56:05

Yeah, yeah. So let me end with one story that I that I also love. This is a real person. Her name is Sai Baba. It's an Icelandic name. She's a very good friend of mine. She raised his two hours here in California where I live. And she was the caregiver for her friend Jerry. She keeps what she calls a wall of angels in her home. This is pictures of Jerry, and also of the dogs that she has loved and lost. She has set a timer so that the wall is lit at night. I said to her, does it doesn't it make you sad to pass by here all the time? No, never. She told me. The pictures give me comfort. They remind me that they are all still with me. I love that the wall of angels.

Rosanne 56:56

I love that. Oh I love that. Yeah. That's beautiful, Connie, that's beautiful. And it's those. It's it is those things. And when we have to go through their things, and we have to decide what we're keeping and what we're getting rid of. And what we're going to put a box in a closet that we're never going to look at, but we can't get rid of it. How many boxes do you have in your house? Don't ask me Please don't ask me. And, but we have to. It's almost like all of these things have their own energy. And I was very specific. When I was looking for, you know, what are we donating? What am I keeping? I was very specific in? Do I feel that is? Do I feel this? Is this connection? It's not? Is it more than just her blouse? Yeah. Is it a connection of something? And if it wasn't, I let it go. I thanked him. I thanked it for its time. I thanked it for the joy that it brought her and and and for me. And I let it go. And it was hard. Yeah. And I feel like sometimes holding on to all of the stuff keeps you in that place. And it's it's it's important to try to separate out between the I'm keeping this because I can't let it go. I don't know why I can't let it go.

But I can't let it go. And I'm going to let this go and let this be for somebody else. But I am going to keep this because that brings me joy. Yeah. Does that. Do you know it's Oh, hard to parse that.

Connie Baher 58:29

I will tell you and I'm embarrassed. But it's funny. But okay, so I was doing exactly what you're talking about. You go through and you parse them and you say, you know, this is old and broken or this, this doesn't have any meaning for me. But so here's the thing, where I'm sitting as I speak to you over to my left is a closet. And there is something in that closet, and I will explain it to you. So while I was caregiving for my mom, you know, would come in and if we were going to go out she would she would get in her wheelchair and she would always say to me, where's my purse? What's my purse? And so I'd say Mom, it's hanging right here on the back of the handle for the wheelchair. And then as soon as we get in, oh, okay, where's my personal and actually, look, I understand that I have dreams at night about losing my purse. I think maybe this is common for a lot of us women. We keep all our stuff in there. Yeah. So I knew I knew how her anxieties were bound up and then the person it mentioned now, toward the end of her life, what was in there was an old pair of glasses and a Kleenex. I mean, because by that time she didn't need credit cards. She was you know, there was an end but it's still where's my person, you know, I ate was a security blanket thing. Okay, so when it came to parsing out all of these things and giving them away, I looked at this part It's a cloth person, sort of a black and white fabric, nothing terribly fancy about it. And I said, if I give this away, she'll kill me. So it is. It is hanging on a hanger in the closet to my left. Because if she ever comes back and says, Where's my purse? I have to have it for her. Does that make some kind of crazy sense?

Rosanne 1:00:25

Oh, it does. It does. I get it. I get it. I totally get it. Yes. Yeah, I think everybody can get that? No. You're not crazy.

Connie Baher 1:00:37

But there it is. It'll, it'll have to be somebody who comes after me will have to be the one

Rosanne 1:00:43

But it's not going to be you.

Connie Baher 1:00:45

It's not going to be me because it's still it's still it still resonates. i It was tied up with it was so important to her and so meaningful to her. Oh, there it is.

Rosanne 1:00:57

I totally get it. I totally get it. Oh my goodness, that's fantastic. That's fantastic. Well, any, any last thoughts to to those of us on this other side of caregiving? Because I don't think I don't think you retire the caregiving mantle. I don't think you recover the care, you retire the caregiving title, you know, once a caregiver, always a caregiver in my book, but do you have any any last parting thoughts to those of us on this side of caregiving?

Connie Baher 1:01:28

You know, I think, yeah, let me give you this, this, this one, the little, it's a little story, I was driving in the car to go see my mom and radio was on. And this fellow, I think he was a minister. And he was saying, Ah, he said, caregiving, when I speak with my parishioners, it is such a blessing. And, yeah, I see you're laughing and chuckling. And I said to myself, what, you know, there I am, because we know all of us caregivers, the exhaustion, the depletion, all of the things, the sense of not doing enough, all of this and the endlessness and where's my life and all of these difficult, difficult things? And I said, if I may use the word, What a crock. I said, What is he know, I'll bet he's just trying out his sermon for next Sunday. Right? So anyway, time goes on. And time goes on. All right. And I have come to think that yes, it is the toughest job you'll ever have. But I think as I have come, and let me say em emerging, I wanted to say come out from the other side, no, I am emerging from the other side. That it is also maybe the most or one of the most meaningful jobs you can ever have. And so I I'm thinking more kindly about the guy. I thought it was flippant, when he said, it's a blessing. I think it's all too easy to say, oh, you know, oh, you're doing God's work. You're doing just wonderful. You're just doing a great job there. But actually, in a very much more quiet, nuanced, profound way. The chance to have held somebody's hand, metaphorically, anyway, as they make their their final journey. Not everybody, not everybody gets the chance. And not everybody steps up to that opportunity. We all know, you know, where's my sister? Where's my brother? You know, why isn't anybody helping me? Well, for whatever their own reasons are, they may not be able to, but if you can summon the courage, the persistence, the sheer willingness to do the job and show up. It really is something I mean, you know, we asked we did the resume of your life, you know, what did you accomplish? What have you done in your life? Boy, I, you know, we may have all had jobs in the, you know, business world or what have you. Maybe accomplished a great deal out there. Wonderful, great. But somehow for me, I think this has to be one of the best, if not, again, most meaningful things that I was able to devote my life to what so? Yeah, so maybe after all, it really when you look back, it can be it can be transformative, and in some senses a Blessing.

Rosanne 1:04:50

A big thank you to Connie Baher for being my guest today. To find more from Connie, visit our website, Conniebaher.com and look for her articles on NextAvenue.org I hope you enjoyed our podcast today. Head over to Daughterhood.org and click on the podcast section for Show Notes including the full transcript and links to any resources and information from today's episode. You can find and review us on Apple podcasts or anywhere you listen to your podcasts. We are also on Facebook, Twitter, and Instagram at Daughterhood the podcast. Feel free to leave me a message and let me know what issues you may be facing. And we'd like to hear more about or even if you just want to say hi, I'd love to hear from you. Also a very special thank you to Susan Rowe for our theme music. The instrumental version of her beautiful song Mama's Eyes from her album Lessons in Love. I hope you found what you were looking for today, information, inspiration or even just a little company. This is Rosanne Corcoran. I hope you'll join me next time in Daughterhood.